

# Vocational perspectives after spinal cord injury

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# Vocational perspectives after spinal cord injury

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**Objective**: To give insight into the vocational situation several years after a traumatic spinal cord injury (SCI) and describe the personal experiences and unmet needs; to give an overview of health and functional status per type of SCI and their relationship with employment status.
**Design**: Descriptive analysis of data from a questionnaire.
**Setting**: Dutch rehabilitation centre with special department for patients with spinal cord injuries.
**Subjects**: Fifty-seven patients with a traumatic SCI, aged 18–60 years, admitted to the rehabilitation centre from 1990 to 1998.
**Main measures**: Questionnaire with items related to vocational outcome, job experiences, health and functional status.
**Results**: Of 49 patients who were working at the moment of SCI 60% currently had a paid job. Vocational outcome was related to a higher educational level. A significant relation between the SCI-specific health and functional status and employment was not found. The respondents who changed to a new employer needed more time to resume work, but seemed more satisfied with the job and lost fewer working hours than those who resumed work with the same employer. In spite of reasonable to good satisfaction with the current work situation, several negative experiences and unmet needs were reported.
**Conclusions**: Despite a high participation in paid work following SCI, the effort of the disabled worker to have and keep a job should not be underestimated.

## Introduction

Quality of life after a spinal cord injury (SCI) depends on the way a patient learns to adapt to the fundamental changes in his life. Active involvement in activities seems strongly related to health and well being.[1–3] From a social point of view return to work is regarded as one of the most important outcomes of reintegration in society.[4,5] In spite of a well-organized social security system in the Netherlands, the chances to resume work are restricted for patients with chronic diseases and disabilities.[2,6,7] The aim of this study was to give insight into the vocational outcome following SCI in the Netherlands, several years after the injury.

Several studies have reported quantitative results of employment status after an SCI and work rates vary from 31 to 48%.[8–11] In a Dutch multicentre study, 37% of pre-injury workers were gainfully employed after the SCI.[12] Several authors identified factors related to return to work.[4,5,8–18] Predictors of vocational outcome often mentioned

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in the literature are age, education level, type of SCI, pre-injury type of job, and disease-specific problems and disabilities. Several subjective factors such as motivation and expectations of the patient regarding return to work will affect the outcome to a great extent.[10,13,18]

In the literature little is known about the working conditions and satisfaction with the job situation after reintegration in work. Satisfaction with the vocational situation after an SCI is usually low, which can be explained by poor-quality jobs and insufficient income.[19–21] With more knowledge about the experiences regarding work the rehabilitation team can teach patients with SCI how to cope with these matters and to help them to sustain work.

The Dutch Organization for Applied Scientific Research (TNO Arbeid) has developed a Vocational Handicap Research Programme to evaluate the working conditions and experiences of chronic disabled people with various diagnoses.[2,6] People with SCI have not been under study yet. In this study the vocational outcome of people with SCI is presented, including the work-related disabilities, changes in working hours, job adjustments and personal experiences of those who are employed.

## Methods

### Patients

In this study we focused on patients with traumatic SCI, admitted to the Centre for Rehabilitation Beatrixoord from 1990 until 1998, aged 18–60 years, and living in the community. Of 89 eligible candidates 14 patients were excluded: four patients deceased, three had serious psychiatric problems, one was discharged to a nursing home and six were foreigners with difficulties with the Dutch language. Two finished their rehabilitation programme in another rehabilitation centre and discharge data were not complete. For four patients addresses were not found and they were lost to follow-up. A questionnaire was sent to 69 patients. It was filled in and returned by 57 patients, giving a response of 83%.

The study group was divided into four subgroups: six patients (11%) had complete tetraplegia (ASIA A), 17 patients (30%) incomplete tetraplegia (ASIA B–D), 20 patients (35%) complete paraplegia (ASIA A) and 14 (24%) incomplete paraplegia (ASIA B–D).

### Questionnaire

Data on the current vocational situation and several health and disability-related characteristics were gathered using a questionnaire that was developed for this study. This questionnaire consisted of relevant items of a questionnaire developed by TNO Arbeid (see Appendix). TNO Arbeid validated their questionnaire in other research projects within the Vocational Handicap Research Programme.[2,6] Data became available on the employment situation both before the injury and after reintegration.

Factors that were related to vocational situation were age, educational level (grades 1–8), time since the injury and several SCI-related variables. A Dutch validated scale by Post[19] was used to evaluate eight health problems related to SCI experienced in the last four weeks before assessment: respiratory problems, pain, spasms, contractures, excessive sweating, oedema, pressure sores, urinary tract infections (score 0–8). The TNO assessment also includes a scale regarding 18 work-related disabilities with response choices 'able', 'able with difficulty' and 'not able' (TNO score 0–54) and six items regarding dependence on help with response choices 'independent', 'partially dependent' and 'dependent' (TNO weighted score 0–42). An estimation of the time used for self-care pre and post injury was asked for and the extra time in minutes currently needed for self-care activities every day calculated.

A description was given of the health and functional status in four subgroups. Several items were used from scales mentioned earlier. The ability to walk functionally with or without devices, and the level of continence for urine with or without bladder management techniques were both assessed on a three-point scale (able, with difficulty, not able). The impact of the health status was assessed by the RAND36 (Dutch version).[22] This measures health perception on nine multi-item dimensions: physical functioning, social functioning, physical role restriction, emotional role restriction, mental health, vitality, pain, general health and health change. A lower score is indicative of a worse health experience.

An overview was given of aspects of the job reintegration and of the current work situation. Respondents were asked to report the time to return to work, vocational retraining, changes in working hours, changes in job or employer, adaptations of the workplace, contacts with professionals, and social benefits. Their opinion on the working conditions and social atmosphere in the current job situation was assessed. Satisfaction with the job ranged from not satisfied to satisfied (grades 1–4).

### Analysis

We defined having paid work as being able to work gainfully for at least 4 h a week. Descriptive statistics were performed using the SPSS version 10.0. Differences in the indicators between groups of patients with and without a paid job were tested using univariate logistic regression analysis and presented using odds ratios. An analysis of variance and multiple comparisons were used to compare the subgroups with different types of SCI regarding health and functional status. The significance level was chosen as $p < 0.05$.

## Results

The study group of 57 respondents consisted of 52 men (91%) and 5 women. Their age at the moment of the SCI ranged from 18 to 59 years with a mean of 33 years (SD 11). The time elapsed since injury varied from 29 to 140 months with a mean of 84 months (SD 29). Twenty-three spinal cord injuries (40%) were caused by traffic accidents, 13 (23%) by industrial accidents, and 21 (37%) by sports and private accidents.

The group of patients who returned the questionnaire ($n = 57$) was compared with the group who gave no response ($n = 12$). There were no significant differences regarding age, gender and type of SCI. The most remarkable difference between the groups of respondents and nonrespondents was the percentage of patients working pre injury. In the group of respondents 49 (86%) were working at the moment of SCI versus 5 (42%) in the group of nonresponders. In the group of nonresponders the time since SCI was on average longer than in the group of responders (Table 1).

**Table 1** Representativeness of the response group (mean (SD) and percentages)

| | Respondents $n = 57$ (83%) | Nonrespondents $n = 12$ (17%) |
|---|---|---|
| Age at SCI (years): mean (SD) | 33 (11) | 34 (14) |
| Gender | | |
| Male | 52 (91%) | 12 (100%) |
| Female | 5 (9%) | 0 (0%) |
| Time since SCI (months): mean (SD) | 84 (29) | 99 (30) |
| Type of SCI | | |
| Complete tetraplegia | 6 (10%) | 2 (17%) |
| Incomplete tetraplegia | 17 (30%) | 4 (33%) |
| Complete paraplegia | 20 (35%) | 5 (42%) |
| Incomplete paraplegia | 14 (25%) | 1 (8%) |
| Job situation at SCI: | | |
| Work | 49 (86%) | 5 (42%) |
| School | 5 (9%) | 4 (33%) |
| Other | 3 (5%) | 3 (25%) |

SD, standard deviation; SCI, spinal cord injury.

### Vocational outcome

At the time of assessment 34 people (60%) had paid work, including 29 working pre injury and 5 students who graduated in the mean time. Table 2 shows that a higher educational level is an important indicator of being employed after an SCI, while age, SCI-specific health and functional status were not significantly related to the current work situation.

### Health and functional status

For the current health status, disabilities and dependence on help see Table 3. Health problems were experienced by 47 (83%) of the 57 respondents in the last four weeks before the assessment with a mean of two problems per individual. More than half of the study population reported pain (56%) and spasms (61%), not significantly related to the type of SCI.

People with complete tetraplegia needed significantly more help with self-care, transport and domestic activities. Complete lesions were associated with a significantly higher number of work-related disabilities, more extra time for self-care and lower perceived physical functioning in the RAND36. None of the other dimensions of health

**Table 2** Comparison of subgroups with or without a paid job regarding personal and SCI-related variables and satisfaction (mean (SD)) using univariate logistic regression analysis (odds ratios (OR) and 95% confidence intervals (95% CI))

| | Paid job $n = 34$ (60%) | No paid job $n = 23$ (40%) | OR (95% CI) |
|---|---|---|---|
| Age now (years) | 38.4 (9.4) | 42.8 (11.9) | 1.0 (1.0–1.2) |
| Educational level * (1–8) | 4.7 (1.8) | 3.5 (1.4) | 0.5 (0.2–0.9) |
| Time since SCI (months) | 89.4 (31.5) | 76.7 (24.2) | 1.0 (0.9–1.0) |
| Health problems (0–8) | 2.2 (1.3) | 1.7 (1.5) | 0.8 (0.4–1.6) |
| Disabilities (0–54) | 15.8 (7.1) | 17.3 (5.2) | 0.9 (0.7–1.2) |
| Dependence (0–42) | 8.1 (9.9) | 12.4 (14.6) | 1.0 (0.9–1.1) |
| Extra time for self-care (min) | 36.1 (35.6) | 47.8 (48.4) | 1.0 (1.0–1.0) |
| Perceived physical functioning (0–100) | 37.0 (28.4) | 25.4 (18.6) | 0.9 (0.9–1.0) |

*$p < 0.05$.
SCI, spinal cord injury; SD, standard deviation.

experience (RAND36) were related to the level and extent of the lesion.

Results on the scale for work-related disabilities (TNO) showed that about half of the study group (47–51%) was not able to stand up, stand, walk, keep balance or climb a ladder. Kneeling and running was not possible for two-thirds (65–71%) of participants, and 30–40% were able to do these activities with difficulty. Two-thirds (63–69%) had problems with bending, lifting and pulling. Sitting, reaching, gross and accurate movements of arms and hands caused problems for about one-quarter (21–26%) of the respondents.

## Job modifications

Return to a paid job took place after an interval of 3–108 months (median 12 months). Eleven of those currently working (32%) followed vocational

**Table 3** Comparison of subgroups with different types of SCI regarding health and functional status and having a paid job (mean (SD) or *n* (%)) ($n = 57$)

| | Complete tetraplegia ($n = 6$) | Incomplete tetraplegia ($n = 17$) | Complete paraplegia ($n = 20$) | Incomplete paraplegia ($n = 14$) | Total ($n = 57$) |
|---|---|---|---|---|---|
| Health problems (0–8) | 2.5 (1.5) | 1.7 (1.3) | 2.4 (1.46) | 1.5 (1.2) | 2.0 (1.4) |
| Pain | 5 (83%) | 7 (41%) | 12 (60%) | 8 (57%) | 32 (56%) |
| Spasms | 4 (67%) | 12 (71%) | 13 (65%) | 6 (43%) | 35 (61%) |
| Disabilities*(0–54) | 26.7 (2.8) | 13.5 (4.5) | 22.9 (2.7) | 13.9 (4.7) | 18.3 (6.4) |
| Walking: | | | | | |
| Yes | 0 | 5 (29%) | 0 | 1 (7%) | 6 (10%) |
| With difficulty | | 11 (65%) | | 11 (79%) | 22 (39%) |
| No | 6 (100%) | 1 (6%) | 20 (100%) | 2 (14%) | 29 (51%) |
| Remain dry: | | | | | |
| Yes | 4 (67%) | 13 (76%) | 3 (30%) | 6 (43%) | 29 (51%) |
| With difficulty | 1 (16%) | 3 (18%) | 7 (35%) | 5 (36%) | 16 (28%) |
| No | 1 (16%) | 1 (6%) | 7 (35%) | 3 (21%) | 12 (21%) |
| Dependence* (0–42) | 33.0 (11.2) | 7.1 (10.4) | 10.0 (9.0) | 2.9 (4.1) | 9.8 (12.1) |
| Help with self-care | 6 (100%) | 1 (6%) | 2 (10%) | 0 | 9 (16%) |
| Help with transport | 4 (67%) | 4 (24%) | 5 (25%) | 2 (14%) | 15 (26%) |
| Extra time for self-care* (min/day) | 68.3 (22.3) | 19.7 (41.3) | 60.0 (41.1) | 28.9 (31.3) | 40.9 (41.3) |
| Perceived physical function* (0–100) | 10.0 (13.4) | 45.6 (27.2) | 17.1 (10.6) | 46.1 (24.0) | 32.2 (25.3) |
| Paid work | 3 (50%) | 9 (53%) | 12 (60%) | 10 (71%) | 34 (60%) |

*$p < 0.05$.
SCI, spinal cord injury; SD, standard deviation.

retraining. At the moment of the SCI the people with a paid job worked on average 48.7 h a week (range 25–100, SD 16.5, median 40), while present job hours averaged 31.6 h a week (range 4–70 h, SD 17.1, median 36). Eighteen people (62%) worked less hours than before the SCI. Thirteen of the 34 working respondents (38%) had a paid job without any supplementary benefit and 21 (62%) worked with benefit from the Dutch Work Disability Act (WDA).

In 25 of the 34 present work situations (74%) modifications had been made. Twenty respondents (59%) received job adaptations such as personal aids and adapted furniture or toilet facilities. Adapted transport was available for six workers (18%). Adjustments in tasks, work tempo and working hours were arranged for 22 workers (65%). Personal time management (planning your own working day) was mentioned by 17 (50%) of the workers. Six respondents (21%) were able to work at home.

In Table 4 we relate the changes regarding job or employer to several reintegration aspects and job experiences. Nine respondents (26%) who had a different job at the same employer experienced the most changes in working hours (89%) and job adaptations (89%). They were all working with full or partial benefits from the WDA. Of 12 people (35%) who had a different employer seven (58%) followed vocational retraining and needed the longest time to return to work. This subgroup showed the least reduction of working hours, the least benefits from the WDA, the least current contacts with work professionals, and the least need for more adaptations. Nine of them (75%) were satisfied with the job.

### Job satisfaction, personal experiences and unmet needs

The assessment of job satisfaction on the TNO questionnaire showed that 22 people (65%) were 'satisfied' with their jobs (grade 4), 10 (29%) were 'reasonably satisfied' (grade 3), one person (3%) was 'little satisfied', and one person (3%) was 'not satisfied' (grade 1). Regarding the experiences in the present work situation 15 workers (44%) reported physical strain, 23 (68%) reported mental strain and 16 (47%) were working under time pressure. Eight (24%) found their work tiring, 12 (35%) mentioned they should calm down in their work and five (15%) that their health was influenced negatively by their work. Most of these workers judged the accessibility positively (88%) and none of them had transport problems. In 15 work situations (44%) the respondents were dependent on their colleagues. Absence due to illness at present was reported by six (18%) of the respondents; three (9%) were absent because of factors related to the SCI. Significant relations between these experiences and the degree of satisfaction with work were not found.

Half of the working respondents had recently had contact with reintegration professionals regarding their health at work. Three of them (9%) still received support from the rehabilitation team. Six (18%) wanted more contacts with (work)

**Table 4** Changes to a different job or employer of respondents currently working ($n = 34$) related to reintegration aspects and current experiences

| | Same employer, same job ($n = 8$) | Same employer, other job ($n = 9$) | Other employer ($n = 12$) | No job pre-injury ($n = 5$) | Total ($n = 34$) |
|---|---|---|---|---|---|
| Reintegration aspects | | | | | |
| Months not working: median (range) | 9 (3–12) | 9 (6–18) | 20 (8–108) | – | 12 (3–108) |
| Vocational retraining: *n* (%) | 1 (13%) | 2 (22%) | 7 (58%) | 1 (20%) | 11 (33%) |
| Change job hours: *n* (%) | 5 (63%) | 8 (89%) | 5 (42%) | – | 21 (62%) |
| Adaptation of workplace: *n* (%) | 6 (75%) | 8 (89%) | 9 (75%) | 2 (40%) | 25 (74%) |
| Current experiences | | | | | |
| Benefit from WDA: *n* (%) | 5 (63%) | 9 (100%) | 6 (50%) | 1 (20%) | 21 (62%) |
| Contacts with professionals: *n* (%) | 5 (63%) | 6 (67%) | 4 (33%) | 2 (40%) | 17 (50%) |
| Wish (more) adaptations: *n* (%) | 2 (25%) | 4 (44%) | 1 (8%) | 0 | 7 (21%) |
| Good job satisfaction: *n* (%) | 6 (75%) | 4 (44%) | 9 (75%) | 3 (60%) | 22 (65%) |

WDA, Dutch Work Disability Act.

professionals. Seven (21%) of the present workers wanted (more) job modifications, especially more personal time management, the opportunity to work at home, or (more) adaptations to the workplace. Two people (6%) were looking for another job with better working conditions, flexible working hours or better salary.

## Discussion

Return to work is regarded as one of the most important long-term rehabilitation goals.[4,5] As the majority of patients with a traumatic SCI are relatively young, attention to social and vocational reintegration is of particular importance, not just to the patients themselves but also from a wider social point of view.[9] A large number of people with SCI in this study were able to work, which was not associated with SCI-specific health and functional status. Educational level was a significant indicator of vocational outcome. In spite of a rather favourable opinion about their jobs, the unmet needs of the workers should not be underestimated.

The cohort under study completed a standard multidisciplinary rehabilitation programme including education, training and counselling, based on goals set by the rehabilitation team in agreement with the patient.[23] In comparing the study with other research on this subject, a high standard of care and support in the Netherlands has to be taken into account. The results are based on patient report, which make them obviously subjective. Because of the small numbers we included all types of SCI. Some factors might have flattered the results of the study group: the small group of nonrespondents had less vocational potential pre-injury, and patients who did not speak Dutch were excluded. A limitation of the study is that socioeconomic and cultural differences within the Netherlands were not analysed.

The percentage of 60% who were currently being employed in the present study was higher than expected. The economy has been booming in the last decade and the Dutch government has stimulated work participation. In contrast to several years ago protection of income by social security is now secondary to having work. The variation in study samples in terms of demographic and injury-related characteristics makes it difficult to compare results of different studies.[8–12,24] In a Dutch multicentre study[12] Tomassen *et al.* reported that 37% of pre-injury workers were gainfully employed after the SCI, which was lower than the outcome in this study. The recruitment of participants was comparable. People in our study group were slightly younger with a little more incomplete lesions and the time since injury was on average longer. Other factors such as socioeconomic and cultural circumstances were assumed to play a role, but were not analysed in this study.

The educational level turned out to be an important indicator of vocational outcome several years after the SCI. Higher levels of education have been found to have a positive relation to employment in several other studies.[4,5,13,15,16,25,26] This highlights the need for increased attention and focus on education and vocational retraining during vocational rehabilitation.[25] Significant SCI-specific indicators were not identified and the vocational outcome was not related to the level and extent of SCI, unlike other findings.[4]

The second part of the study describes current work-related disabilities, job adjustments, working conditions and experiences in the present job situation. The outline of the health and functional status of participants shows that the impact of SCI is greater for people with complete SCI, which is indicated by the level of disabilities and perceived physical functioning. The high dependence score of people with complete tetraplegia illustrates the level of the dependence on others with several daily activities. Despite the serious consequences of the SCI this should never be a reason to exclude people with SCI from the labour market without exploring vocational possibilities. Participation in the employment process of people with chronic disabilities has been an important point of political interest in the Netherlands for the last decade and equal opportunities for people with a chronic disease are laid down by law. Individual job counselling and vocational services are formally available for all people with vocational handicaps. The vocational outcome in this study did not show a significant difference between the subgroups.

Preceding their SCI a large part of this study group spent on average more than 40 working hours a week pre-injury on physically demanding

**Clinical messages**

- People with SCI have rather good vocational perspectives.
- As working with an SCI demands a more than average effort, ongoing vocational guidance is essential.

jobs. It included a relatively high number of self-employed workers and people who extended their regular jobs with jobs on the side in evening hours. Two-thirds of the participants underwent on average extensive changes in working hours. Employees reduced their average working hours to two-thirds and self-employed workers to half of their previous hours. Financial consequences were often at least partially compensated by means of the Dutch Work Disability Act (WDA) or insurance benefits, which makes it attractive to carry on working. The principle work-related disabilities are loss of mobility and to a smaller extent loss of use of arms and hands. Continence problems were common. Job adjustments and adaptations of the workplace are often needed to return successfully to former and new jobs.

Regarding reintegration interventions and experiences, several differences were found between people who kept working at the same employer and those who changed to a different employer. Numbers were too small to give a statistical analysis. The first group reintegrated relatively fast with various adjustments and loss of working hours. The employer is obliged to support all measures needed to reintegrate in work. People who had to find a new employer received more vocational retraining and needed more time to return to work. It is more difficult for disabled workers to find a new job with a new employer, so long-term counselling of this group is essential.[27] However, it seems that for this group working hours are less often reduced and people are less dependent on the WDA and more satisfied with their job. This might be explained by the fact that new jobs are less physically demanding and match better with the disabilities. A prospective study is necessary to test the hypothesis that people who changed to a new employer were more likely to stay in work in the long run.

The main goal of the Vocational Handicap Research Programme of TNO Arbeid was to describe the working conditions and experiences of chronically disabled people with various diagnoses, to create a more positive image of their capabilities to (potential) employers and policy-makers.[2,6] The personal experiences of working respondents in our study were reasonably positive. Most of them were fairly satisfied or satisfied with their jobs, which is comparable to the experiences of other disabled workers.[6] Nevertheless, the negative experiences associated with work such as mental strain, working under pressure, insufficient consideration of colleagues and bosses, and absence due to illness, are relatively high compared with a nonhandicapped reference population.[28] As in other studies of the Vocational Handicap Research Programme a substantial number of workers wanted more adjustments and contacts with professionals. Employees are less satisfied if they feel a need for further adaptations in the workplace and experience negative social effects due to their disorder.[2] This calls for ongoing efforts of professionals to support this group with SCI with interventions that fit personal requirements. Reducing time pressure demands, increasing freedom in personal time management and the opportunity to work at home seem preferable.[2]

In-depth interviews are needed to gain more insight in the vocational handicaps and personal experiences of those who returned to work following a SCI, to enhance the quality of individual counselling and effective interventions.

In conclusion, people with SCI have rather good vocational perspectives. However, working with an SCI demands more than average effort. Vocational guidance should not be restricted to the rehabilitation and following reintegration period, but to be continued in the long run to keep people with SCI at work.

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## Appendix – Questionnaire for workers as part of the Vocational Handicap Research Programme of TNO Arbeid

Items not used in this study are in italics.

1) Disease-specific items:
   - *Impairments (loss of strength)*
   - Disabilities regarding work-related activities
   - Dependence on help with self-care, domestic activities, transport
   - *Complaints/symptoms*
2) Health: assessment of health perception on nine dimensions (RAND 36)
3) Income
4) Educational level
5) Pre-injury employment situation: type of job, job contract, working hours
6) Current employment situation: type of job, job contract, working hours
7) Job modifications:
   - Change of job or employer
   - Material and immaterial adaptations of the job
8) Opinions about the current working conditions and social atmosphere:
   - Job satisfaction
   - Personal experiences regarding the job
   - Accessibility and transport
   - Relationship with colleagues and boss
   - Possibilities for promotion
   - Influence of job on health
   - Wish for (more) job modifications
   - Absence due to illness
   - Contacts with work professionals
   - Wish for (more) contacts with work professionals
   - Looking for another job